

Misinformation and Misbeliefs in the Tuskegee Study of Untreated Syphilis Fuel Mistrust in the Healthcare System

Robert M. White, MD, FACP
Silver Spring, Maryland

The Tuskegee Study of Untreated Syphilis (TSUS) is an important issue in research, healthcare, ethics and race relations. The assumed consequences of knowledge of this study on the African-American community include mistrust of the healthcare system.

In the July 2005 issue of the *Journal of the National Medical Association*, Brandon, Isaac and LaVeist (the authors), who were at the Center for Health Disparities Solutions, Johns Hopkins Bloomberg School of Public Health, reported the results of black-white differences in awareness of and knowledge about the TSUS and the effect of that awareness and knowledge on medical mistrust. The study surveyed blacks, whites and others in the Baltimore, MD community about their knowledge of and attitudes about the TSUS. The respondents who were aware of the TSUS were asked survey items to assess specific factual information about the TSUS. The respondents who were not aware of the TSUS were read a brief description of the TSUS taken from the CDC website. Both groups were asked if a similar study was possible today. The authors performed a regression analysis of mistrust of medical care based on race, knowledge of the TSUS and demographic variables.

The editorial identified and explained challenges in the article, i.e., challenges in calculations, demographic analysis by race, knowledge of TSUS, cultural sensitivity and methodology. The authors miscalculated the "similar proportions" of blacks and whites who were aware of the TSUS; the recalculated proportions, favoring whites, were different than reported by others. There was no demographic analysis by race in their article—also different than other published reports. Most respondents—blacks and whites—who were aware of the TSUS at baseline answered incorrectly the author-selected questions about the TSUS, particularly the fact-based question of whether the TSUS researchers gave syphilis to the men—not dissimilar to one other report. The source for TSUS information (the CDC website) that was used to educate respondents who were not aware of the TSUS at baseline had contradictions, errors and challenges in black history, medical and public health history, and women's studies. The content of what was actually read to respon-

dents was unknown. Proportionally more whites who were not aware of the TSUS but who were read author-selected information about the TSUS believed that a similar study could happen today—a belief and possibly mistrust of medical care that appeared to be induced—compared to whites with prestudy awareness of the TSUS but not read information from the CDC website. Both black groups were not dissimilar from each other. The authors used a survey that measured a race difference in response to a medical event (TSUS) specific to only one racial group (blacks) when there were inclusive examples specific to other groups available. The authors used "Tuskegee" as a single-word sound bite for the TSUS—a misuse that was inappropriate in scientific and research discourse and that may fuel mistrust of medical care.

Whether knowledge of the TSUS was a predictor of mistrust of the healthcare system was inconclusive based on the results in the authors' article. The core findings of the article made believing their case difficult. The editorial suggested that bias and misinformation in undertaking, analysis and reporting the study may in itself fuel mistrust in medical care in the community. Because of these challenges, the editorial urged caution with regard to any change in research direction or policy debate based on the results reported in the article.

Key words: Tuskegee Study of Untreated Syphilis ■ medical care mistrust ■ miscalculations ■ racial differences ■ misinformation

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The Tuskegee Study of Untreated Syphilis (TSUS) is an important platform to examine issues of race in medicine and research. The TSUS was the 1932–1972 U.S. Public Health Service (USPHS) study in rural Alabama. Two groups of black men were followed to autopsy—approximately 400 syphilitics found untreated and a comparable group of approximately 200 presumably nonsyphilitic men.¹ The assumed consequences of knowledge of this study on the African-American community

include mistrust of the healthcare system in which blacks: a) have worse health outcomes than whites; b) do not participate in clinical trials; and c) do not participate as organ donors.²⁻⁴

However, distortions about the TSUS have crept into the information database, possibly fueling the mistrust of the health system in the black community. These distortions may continue to contribute to mistrust and ineffective doctor–patient and researcher–participant relationships, and risky health behaviors among some persons. The cumulative effects may contribute to wide health disparities to the disadvantage of the black community. In addition, past and current historical misinformation about the TSUS may contribute to stereotypes and negative feelings and behavior between and among various racial and ethnic groups in the general population. It appears that an emphasis on negative events can promote allegedly poor health behaviors in the black community (e.g., the myths surrounding the death of Dr. Charles Drew^{5,6}). Over a hundred years ago, this was not the response by black physicians, other professionals and community leaders, when for example, there was a threat of African Americans’ extinction.⁷ Thoughtful and healthful construction of policies, programs and procedures were the order of the day and were responsible for reversal of this threat.

In the July 2005 issue of the *Journal of the National Medical Association (JNMA)*, Brandon, Isaac and LaVeist (the authors) reported the results of black–white differences in awareness of and knowledge about the TSUS and the effect of that awareness and knowledge on medical mistrust.⁸ The authors, based at the Center for Health Disparities Solutions, Johns Hopkins Bloomberg School of Public Health, focused on an important issue in research, healthcare, ethics and race relations. The study surveyed blacks, whites and others in the Baltimore, MD community about their knowledge of and attitudes about the TSUS. The sample from Baltimore was a subset from a larger study to assess mistrust of the healthcare system in subjects in Washington, DC; New York City; and Baltimore. The authors chose that city because Baltimore: a) has a “large African-American population”; and b) “has a long-standing, economically diverse, yet relatively segregated black population.” The authors did not provide similar information about whites and others in Baltimore who might have been selected for study. The authors asked all the subjects “if they had ever heard of the Tuskegee study.” Subjects who had heard of the TSUS were asked five questions to assess their knowledge of the TSUS, plus they were asked “if a similar study was possible today.” The subjects who had not heard of the TSUS were read a

brief description from the CDC website and then asked “if they thought a study like the Tuskegee study could happen today.”

CALCULATIONS

There were several calculation challenges. In their 2003 study, the authors surveyed a sample of 401 respondents ≥ 18 years of age in Baltimore City (277 blacks, 101 whites, 23 other). They wrote that “Approximately two-fifths of the total sample (41.9%, $n=168$) had heard of the Tuskegee study.” They further wrote that “there were no significant race differences in awareness of the study, with similar proportions among black (41.7%, $n=70$) and white (44.6%, $n=75$) respondents reporting having heard of the Tuskegee study.” The authors miscalculated the “similar proportions” of blacks and whites who were aware of the TSUS by dividing the number of blacks (70) who knew about the TSUS by the subset who knew about the TSUS—composed of blacks, whites and others (168), or $70/168$ and for whites $75/168$. The denominator for each respective race should have been 277 for blacks and 101 for whites^a—the total number of blacks and whites in their survey, giving strikingly different proportions for awareness about the TSUS by race, i.e., $70/277$ or 25.3% for blacks, and $75/101$ or 74.3% for whites.

Three other studies placed these results in context. First, in 1994, Green and colleagues surveyed a sample of black and white persons ≥ 18 years in Jefferson County, AL. They found that 52% of blacks ($n=112$) compared to 46% of whites ($n=92$) had knowledge of the TSUS.⁹ Second, in 1998, Brown and Topcu surveyed a sample of persons ≥ 50 years of age in the metropolitan Detroit area. They found that 55% of blacks ($n=208$) compared to 38% of whites ($n=211$) had knowledge of the TSUS.¹⁰ Third, in 1998–1999, Shavers and colleagues surveyed a sample of persons ≥ 18 years in the Detroit Primary Metropolitan Statistical Area. They found that 81% of blacks ($n=91$) compared to 28% of whites ($n=88$) had knowledge of the TSUS.¹¹ Brandon, Isaac and LaVeist did not document and/or explain in the review of literature in their article their markedly different proportions of awareness of the TSUS, favoring whites.

There was no demographic analysis by race in the authors’ demographics table. Demographics by race may have provided insight into the markedly skewed results of awareness of the TSUS in the direction of whites. Lack of demographic analysis by race was not only a deviation from the standard of how others who performed this type of research have presented their results,⁹⁻¹¹ but this deviated from the way one of the authors presented demographic data in a recently published article.¹² It was also noteworthy that there was no

breakdown of the race group identified as “other,” i.e., Asian, Hispanic or “not identified”. There were 23 “other” respondents in the total sample. In the subset with awareness about the TSUS, there were 23 “other” respondents (168 – [70 blacks] – [75 whites]=23) or 100% of the “other” respondents were aware of the TSUS—another strikingly surprising result. The authors did not provide the readers of the *JNMA* with appropriate information for understanding their results. Although the authors might claim that their model adjusted for confounding demographic variables, based on their miscalculation of the core findings of the study, the readers of the *JNMA* may want to reserve trust that this was the case.

In the authors’ Table 2, “Knowledge about Tuskegee among Respondents Aware of the Tuskegee Study,” the correct answers to the five author-selected questions were presented in bold. The answer “yes” to their sixth question—“Do you think it possible for a study like this to occur today?”—was also presented in bold, which may indicate author bias. Also, the sixth question total percentage responses did not add up to 100%, i.e., 94.5% for blacks and 91% for whites. For reasons that were not specified, the number of respondents for this question was 378 or the total of black and white respondents, instead of 145, which was the number for the other five questions.

The table that contained the results from the regression analysis of mistrust of medical care based on race, knowledge of the TSUS and demographic variables was unique. This was the only table of the four tables that did not have “n=”, giving the reader a numeric value for the number of respondents entered into the model. As will be explained in the next section, there were two populations of respondents, i.e., a population who was aware of the TSUS at baseline and a larger population that was not aware of the TSUS at baseline but who were read author-selected information about the TSUS. If the latter population of respondents were entered into the model, their inclusion might have biased the results because of author intervention. Also, the reader was left to conjecture about the validity and reliability of the regression model because the citation in the references for this information was still “under review” at the time of publication.

KNOWLEDGE ABOUT THE TSUS

There was knowledge about the TSUS challenges with regard to the respondents and the sources for TSUS information.

The authors asked the respondents who were aware of the TSUS (70 blacks, 75 whites) survey items to assess specific factual information about the TSUS. The source of the factual information was not

referenced nor was there any insight into why knowing about these facts and specific aspects of the TSUS were important or could have any impact on mistrust of the medical system. In their introduction, the authors described the TSUS as a study that “lasted for approximately 40 years,” “involved the intentional deception and denial of treatment of the research subjects” and “represents the model example of the type of harmful experimentation feared by many African Americans.” Questions and answers about the decade when the study began or ended, the number of men in the study and what organization conducted the study do not appear to provoke fear. Except for the correct decades for the beginning and ending of the study—1930s and 1970s—only the incorrect “begin” and “end” decade choices of 1890s and 1930s gave an approximate 40-year duration of the study; none of the other combination choices gave a 40-year duration. However, a question about whether or not the researchers gave the men syphilis might provoke fear and was the most revealing question asked to respondents. Although the TSUS researchers did not give the men in the study syphilis, a majority of both blacks and whites answered this fact-based question wrong (75% vs. 53%, respectively). Shavers and coauthors reported similar results in their survey of blacks and whites who were familiar with the TSUS, i.e., 76% of blacks and 59% of whites believed the men in the TSUS were injected with syphilis by the researchers.¹³ In fact, except for the question about when the study began, the majority of the subjects answered the questions incorrectly. Furthermore, there was no indication that an educational intervention to remedy these knowledge deficits about the TSUS was rendered—particularly, the erroneous belief that the TSUS investigators injected the men with syphilis. This myth that might fuel mistrust in medical care should have been documented in the article as dispelled in the authors’ sample of respondents.

The respondents who did not know about the TSUS (i.e., 207 blacks, 26 whites) were read “a brief description (taken from the CDC website).” After this educational intervention, they were asked if they believed a study like the TSUS could happen today; it may have been more interesting to ask them the same questions as the respondents who were aware of the TSUS at baseline and not read “a brief description.” In fact, there was no indication of exactly what the content was that these respondents were provided. In addition, there was no information about whether the content covered information required to answer the knowledge about the TSUS questions that were asked of the respondents who were aware of the TSUS. This was important, considering that 64% of white respondents who were provided this information believed that a similar

study could happen today, compared to 38% of white respondents who had prestudy awareness of the TSUS and who were not read “a brief description” of the TSUS. Of course, this retrospective subset may have credence if the two white groups were demographically similar, but the readers of the *JNMA* do not have this information. Black respondents who were provided this information compared to black respondents who had prestudy awareness of the TSUS and not read “a brief description” of the TSUS were not fundamentally different (77% compared to 87%, respectively); both black groups strongly believed it could happen today. Again, readers do not know whether these two groups of respondents were demographically similar.

Nevertheless, more than a few words are in order about the challenges, including contradictions and errors, in the CDC website describing the TSUS. Similar to standard information sources about the TSUS, there were substantial challenges in the CDC website with regard to black history, medical and public health history, and women studies.¹ There are two main websites with other links about events related to the TSUS, i.e., “Tuskegee Timeline”¹⁴ and “More Information.”¹⁵

First, none of information in either website was referenced and, thus, it was unknown whether the information was derived from primary sources in CDC archives and publications from the times or from books and more recent peer-reviewed articles about the TSUS. The “Timeline” did not agree with itself, regarding when penicillin became the drug of choice for syphilis, i.e., 1947 in the section “What Went Wrong?” and 1945 in the chronology; the “More Information” website had 1947. An article in the *JNMA* hailed penicillin as the miracle drug and stated retrospectively that the drug was available in 1946.¹⁶ However, a 1948 *JNMA* editorial, in reference to penicillin, stated prospectively that, “Literature which lauds only merits without subjection to long term observation is to be viewed with skepticism. The syphilis cure claims fit this category.”¹⁷ In another prospective 1947 article, the rationale for the use of penicillin in previously untreated latent syphilis—the men in the TSUS—was based on effects on measurable lesions, safety and convenience—not efficacy in late latent syphilis.¹⁸

Second, the “Timeline” website stated that in 1947 the USPHS established “rapid treatment centers.” The rapid treatment center program was established in or before 1943.¹⁹ In the “Timeline,” the statement about the “rapid treatment centers” continued with “men in study are not treated,” but this was not corroborated by what the USPHS wrote prospectively in one of their publications. The USPHS wrote that some of the men in the TSUS

were “inadvertently rounded up and sent to rapid treatment centers.”²⁰

Third, although the “Timeline” website stated that a class-action lawsuit was filed by the National Association for the Advancement of Colored People (NAACP), the attorney for the men denied that the NAACP assisted him in “conducting legal research, drafting pleadings, filing briefs, and financing the case.”^{21(p. 83)}

Fourth, in the “Timeline” the name of Robert Moton is misspelled (i.e., Motin ([sic])).

Fifth, the “Timeline” showed a black man, a black woman and white men involved with the study and named a black woman and black man involved with the study. The “Timeline” did not identify any of the white women and men who had their names on the publications.¹

Sixth, although a photograph cannot be “read” over the telephone, the “Timeline” did have a distorted photograph that gave the wrong message about the conditions that the research in the TSUS were carried out. The photograph of a woman measuring a participant in the TSUS while a man recorded the data in what appeared to be dilapidated surroundings actually was a composite of the photograph taken at the Tuskegee Veterans Administration Hospital in 1952 superimposed with 1999 interior photographs of the long-closed John A. Andrew Memorial Hospital (JAAMH); the dilapidation is from the photograph of the closed and neglected JAAMH. This was egregious because the actual undistorted photograph was contained in the CDC archives stored in East Point, GA (CDC, TSS, Box 34, folder 11, photo #7) and presumably assessable to the CDC staff responsible for the website. The distorted composite may have been taken from a 2003 article in the *Radcliffe Quarterly*.²²

Seventh, the “Timeline” statement, “wives, widows, and children who had been infected because of the study,” was incorrect based on: a) the natural history of syphilis (i.e., older latent syphilitics were presumably noninfectious, and younger syphilitics had treatment to render them noninfectious);²³⁻²⁵ b) the programs and procedures of the Alabama mass survey in the 1940s (i.e., the mandatory mass survey should have detected infected wives and children);²⁶ and c) a HEW ad hoc panelist correspondence—“The evidence now suggests that all women and children with syphilitic infection at any stage were, after 1932, always treated if they could be found.”²⁷

Eighth, the “Timeline” website claimed that the advisory panel concluded that with regard to the TSUS, “the knowledge gained was sparse when compared with the risks.” This was arguable based on another analysis and interpretation of the research.^{28,29(p. 553-554)}

Ninth, in the “Timeline” a claim was made that “127 black medical students are rotated through unit doing the study” from 1947 to 1962. No further details or citation were provided, leaving the reader to conjecture. Based on the information in the CDC website, one might accuse the authors, albeit unknowingly, of spreading flawed and incendiary information in the Baltimore City community and fueling mistrust of the medical care.

Any information provided to the group not aware of the TSUS at baseline beyond the information in the five questions asked of the group of respondents who were aware of the TSUS at baseline would bias that group. Although it was not reported whether the “educated” TSUS-unaware group was asked the same questions as the TSUS aware group, they might be “more knowledgeable” than the group not provided the information. Buried within these two different populations might be evidence that flawed information can fuel mistrust of the medical care. At least in the authors’ Model 3 of their medical care regression analysis with “heard of Tuskegee” as a variable, this biased group might have been included in the calculations. In general, the readers were not informed whether the regression analysis was limited to the group of blacks and whites who were aware of the TSUS at baseline (n=145) or the entire black and white sample (n=378). Furthermore, the authors did not fully disclose the items in the Medical Mistrust Index; this deviates from what other articles have done,⁹⁻¹¹ especially since the Medical Mistrust Index validation manuscript was still “under review” and not available at the time of publication.

CULTURAL SENSITIVITY

There were cultural sensitivity challenges with regard to methodology and the use of a single-word sound bite for the TSUS.

The authors made the points that “blacks were more likely to believe that a similar study could happen again regardless of their awareness of the Tuskegee study” and “we cannot be sure how knowledge of the Tuskegee study may be related to medical mistrust in other minority groups.” We learned from recalculation of the authors’ data that 25% of blacks, 74% of whites and 100% of “others” were aware of the TSUS. However, the authors’ survey measured a race difference in response to a medical event specific to only one racial group. The TSUS was a study that occurred in blacks and whose importance might be more specific to, and thus more meaningful, to blacks. The authors did not vary medical events specific for whites, i.e., linking a medical event, with actual or alleged challenges, that could either pose a potential barrier to participation or induce distrust in the medical care system or

research. Because of this narrow view, one might consider this omission as culturally insensitive,³⁰ i.e., assuming that an adverse medical event specific to blacks influenced behavior in subjects of another race. For example, specifically, “Being the greatest victims of the fairly recent racist Nazi ideology, Jews may have a heightened sensitivity to medical research and to genetic studies in particular.”³¹ There was no evidence to support the assumption that the TSUS influenced health beliefs and behaviors in the same manner in all ethnic groups; ethnic-specific aberrant medical events might be more important to members of a given ethnic group. In view that recalculation of the author’s results for awareness of the TSUS demonstrated nearly a three-fold greater awareness of the TSUS favoring whites over blacks, this type of control might have been useful.

Nevertheless, lack of a comparable medical event specific for whites appeared to be a common methodological flaw in this type of research (i.e., knowledge of the TSUS) in comparing blacks to whites (or other groups).^{9-11,32} Also, in discussions of sociocultural issues in research, only blacks linked to the TSUS as aberrant research were cited.³³⁻³⁵

For the record, there are examples of questionable medical events, which had other races or vulnerable groups, such as (medical event: race or vulnerable group): a) Mengele’s “twin experiments” at Auschwitz: Jews;³⁶ b) Dachau artificial production of septicemia: Polish Catholic priests;³⁷ c) Dachau induced malaria infections to investigate immunization and treatment: concentration-camp inmates;^{38(p. 292-294)} d) induced *Plasmodium falciparum* infections to study development of immunity: black and white neurosyphilitics;³⁹ e) Stateville Penitentiary induced *P. vivax* infections for antimalarial drug screening: white prisoners;⁴⁰ f) radium implants into nasopharyngeal hyperplastic lymphoid tissue: white World War II Army Air Force pilots;⁴¹ g) Sing Sing Prison inoculations of syphilis: black, white and Puerto Rican prisoners;⁴² h) the first contraceptive pill experiment: Puerto Rican women;⁴³ and i) the injection of live cancer cells at the Jewish Chronic Disease Hospital: whites.^{38(p. 9-65)} Dissimilar to the TSUS, in a number of the examples, the researchers injected the research participants with an infectious material—an event that did not happen in the TSUS. Similar to the TSUS, there was no evidence of informed consent in these cases.

Clearly, the medical events listed above are not reported to effect participation of the specific racial groups in clinical trials or fuel mistrust of the health-care system similar to the alleged effect the TSUS has on blacks. Lack of interest by researchers and subjects about and/or citation of other aberrant medical events may occur because: a) these studies may

not be as incendiary and/or as well-known by both researchers and participants; b) other racial or subject groups may be immune to or not interested in past events which included/targeted their group; c) these studies and/or events are protected by specific advocacy groups; d) their influence may not have been consistently studied or published; e) media sources (e.g., print and broadcast press, theater, movies) have not consistently focused on the events; and f) funding agencies may not have shown an interest because of similar reasons and/or other funding priorities.

Finally, in the text the authors referred to the TSUS as the “Tuskegee Study of Untreated Syphilis in the Negro Male,” and “Tuskegee study,” in the title, header, tables, and at times in the Discussion they referred to the TSUS as “Tuskegee” [e.g., *Legacy of Tuskegee* (title); *Tuskegee and Mistrust of Medical Care* (header); *Knowledge about Tuskegee* (Table 2); *Awareness of Tuskegee and Belief that a Similar Study Could Happen Today, Can Tuskegee Happen Again, Unaware or Aware of Tuskegee* (Table 3); *Knowledge of Tuskegee, Heard of Tuskegee, Tuskegee Summary* (Table 4); move beyond Tuskegee and a Tuskegee-like experiment (Discussion)]. This type of “sound bite” and abbreviated labeling and language is inappropriate in scientific and research discourse because misuse of “Tuskegee” may fuel mistrust of medical care. Other authors have used “Tuskegee” in a similar manner, suggesting that this is a common practice.^{10,13,32,33,44} On the other hand, Carmichael and Hamilton associated “knowledge of Tuskegee” with several notables, such as: Tuskegee Institute (now University), Booker T. Washington, George Washington Carver, Tuskegee Veterans Hospital, Tuskegee Civic Association and black World War II Army Air Force pilots (now Tuskegee Airmen). Misrepresentation and misuse of the word “Tuskegee” distracts from the major positive impact of “Tuskegee” on the black experience, community and the nation during decades of severe racial subjugation, segregation and socioeconomic oppression.^{45(p. 122-145)}

DISCUSSION

The core findings of the Brandon, Isaac and LaVeist article made believing their case difficult. It was not true that “approximately two-fifths of both black and white participants” indicated that they had heard of the TSUS, but it was 25% and 74%, respectively—results markedly different than what others have reported. Miscalculations similar to the ones described, if applied to other areas, could cause numerous health disparities to vanish literally on paper when they still exist to the disadvantage of the black community. It was true that there was little dif-

ference between these black and white respondents in detailed knowledge about TSUS—most answered incorrectly the author-selected questions. The authors exaggerated that “nearly twice as many black respondents believed that Tuskegee study research investigators infected the study participants with syphilis” (75.3% vs. 52.8%)—not supported by the data. It was not an exaggeration that nearly twice the proportion of white respondents believed that TSUS research participants already had syphilis (24.7% vs. 47.2%)—supported by the data.

The reason for awareness of the TSUS favoring whites might be due to: a) a random event; b) demographics, such as educational status [e.g., high school, college or advanced college degrees or socioeconomic status (e.g., high, middle, low)]; c) an event occurring in Baltimore that drew selective attention to whites; or d) differences in an individual’s reality and perceptions of community experiences. The authors gave a rationale for selection of blacks from Baltimore, but no rationale for whites was provided. No demographic analysis by race was provided. At least in blacks, media attention directed to the TSUS or some other event might have influenced, in part, the proportions of who knew about the TSUS or any racial difference in response to queries about the TSUS. Corbie-Smith and co-authors suggested this possibility in their report on focus group interviews about clinical research.⁴⁶ They wrote that “... all focus group interviews were completed before national media attention focused on the February release of the Home Box Office special ‘Miss Evers’ Boys’ ... Current interviews may reveal a higher level of awareness of the Tuskegee Syphilis Study ...” In a monograph by Brown and Herskovitz, knowledge of the TSUS in blacks increased from 40% in 1996 to 53% in 1998.⁴⁷ The authors of the monograph wrote, “This finding is not surprising in that President William J. Clinton issued a national apology to the remaining experiment survivors and their families in 1997.” A similar analysis in whites was not performed because the 1996 survey focused primarily on blacks.

Among subjects who were aware of the TSUS, blacks and whites diverged with regard to the belief that a similar study could happen today—87% of blacks vs. 38% of whites believed that it could happen today. Both blacks and whites who were unaware of the TSUS but who received author-selected information about the TSUS similarly believed that it could happen today—77% vs. 64%, respectively. For those who did not have prestudy awareness about the TSUS, education with possibly questionable information about the TSUS might have impacted their trust of the medical care. In other words, blacks and whites who did not know about the TSUS and who were read the same information about the TSUS responded similarly to a

question regarding whether a similar study could happen today. This belief appeared to be induced in whites compared to whites with prestudy awareness of the TSUS but not read information from the CDC website. The duration of this induced mistrust of medical care ("The belief that a similar study could happen again") in whites by what might be questionable information about the TSUS is unknown. From a human subjects perspective, there was no indication that an intervention was available for subjects who were provided information about the TSUS and who now had mistrust of medical care and might suffer harm in their future interactions with medical care. The respondents who were aware of the TSUS at baseline were different than the respondents who were not aware of the TSUS at baseline because the latter group was provided with author-selected information about the TSUS. It was not clear whether only the former group was entered into the authors' medical care mistrust model or whether both groups were used. The fact remains that the latter group was biased.

Whether the TSUS was a predictor of mistrust of the healthcare system was inconclusive based on the results in the authors' article. However, as Brandon, Isaac and Laveist concluded, other researchers also suggested that knowledge of the TSUS might not have the impact on health-related decisions as often alleged. In the Shavers and coauthors article, 49% of blacks who reported that their knowledge about the TSUS would affect their participation in a clinical trial indicated that they would not be willing to participate; 17% of whites indicated the same.¹¹ Conversely, 51% of blacks and 83% of whites may be willing to participate in a clinical trial. Green and coauthors reported that 22% of blacks compared to 10% of whites indicated less interest in participation in health research or promotions because of the TSUS.⁹ This might mean that 78% of blacks compared to 90% of whites were interested in participation. In the Brown and Topcu article, 60% of blacks who had knowledge of the TSUS compared to 64% who had no knowledge were willing to participate in clinical cancer treatment trials; 76% of whites who had knowledge of the TSUS compared to 68% who had no knowledge were willing to participate in clinical cancer treatment trials.¹⁰ Similar to the Brandon, Isaac, LaVeist article, knowledge of the TSUS alone did not appear to influence negatively the willingness to participate in a clinical trial or health promotion. With regard to a difference in an individual's reality and perceptions of community experience, Green and coauthors in their telephone survey reported that 23% of blacks felt unfairly treated because of ethnicity while pursuing help for a health problem, in comparison to 12% of whites.⁹ This might indicate their individual experience with the healthcare system. Over two-thirds of

blacks believed that people were treated poorly in research studies, people were sometimes treated poorly by doctors and African Americans were treated poorly in health research studies; the responses for whites were 55%, 76% and 37%, respectively. This may be an indication of their perception of what others are experiencing in the healthcare system. Corbie-Smith and coauthors' study of distrust and the healthcare system reported that 25% of blacks believed that physicians have given them treatment as part of an experiment without their permission, in comparison to 8% of whites, indicating their individual experience with the healthcare system. Sixty-three percent and 79% of blacks thought that physicians prescribed medication as a way of experimenting on people without their knowledge or consent and thought they or people like them might be used as "guinea pigs" without their consent, respectively; the responses for whites were 38% and 52%, respectively. For both races, this may be an indication of their perception of what others are experiencing in the healthcare system.⁴⁸ Thus, the perception of abuse in the community—"people" and "African Americans"—was higher than the individual's actual reported experience with abuse in the healthcare setting.

In conclusion, it is a laudable goal to attempt to provide evidence that the TSUS does not have an impact on alleged mistrust, but the Brandon, Isaac and LaVeist article has serious challenges in calculations, demographic analysis by race, knowledge of TSUS, cultural sensitivity and methodology. Although these challenges do not minimize the concern that blacks may be making health-related decisions based on medical events or some other event(s), these challenges suggest caution with regard to any change in research direction or policy debate based on the results reported in the article.

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